Perception of quality of life in caregivers of patients with dementia

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Abstract

Introduction: Individuals with dementia suffer from changes at a cognitive, emotional, and behavioural level. These changes can also affect the quality of life of their caregivers in a physical, psychological, social and spiritual dimension.

Objective: Determine the perception of life quality, taking into account the burden of caregivers of patients with dementia.

Method: A descriptive, correlational and cross-sectional study was conducted on an intentional sample of 50 caregivers of patients diagnosed with dementia. The information was collected using three tools: socio-demographic variables, quality of life, and dimension of caregiver’s burden.

Results: The sample consisted of 80% women, with an age range of 36–59 years, of whom 54% were married. More than three-quarters (78%) of them had been a caregiver for more than 37 months, and 66% dedicated 24 h to the work of caring. The main caregivers experience a low care burden and low effect on their quality of life.

Conclusions: The study shows the presence of women in the role of caregivers, the relationship between the quality life and burden, and how they are influenced by the physical and psychological dimensions. Similarly, a low social well-being negatively influences the quality of life.

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KEYWORDS
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Percepción de calidad de vida en cuidadores de pacientes con demencia

Resumen

Introducción: La demencia es una enfermedad que produce en la persona que la presenta cambios a nivel cognitivo, afectivo y comportamental, estas alteraciones pueden afectar la calidad de vida del cuidador en sus dimensiones físicas, psicológicas, sociales y espirituales.

Objetivo: Determinar la percepción de la calidad de vida, teniendo en cuenta la sobrecarga en cuidadores de pacientes con demencia.

Método: Estudio descriptivo, correlacional, transversal, muestra intencional con 50 cuidadores de pacientes diagnosticados con demencia, se recolectó la información mediante 3 instrumentos: caracterización sociodemográfica, calidad de vida y sobrecarga del cuidador.

Resultados: Mujeres en un 80%, con rango de edad de 36 a 59 años, 54% casados, 78% llevaba más de 37 meses como cuidador y 66% dedican 24 h a la labor de cuidado; los cuidadores principales experimentan baja sobrecarga y baja afectación en su calidad de vida.

Conclusiones: El estudio muestra la presencia de las mujeres en el rol de cuidador, así como la relación entre la calidad de vida y la sobrecarga e influyó de manera negativa en la calidad de vida.

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Introduction

Dementia is a worldwide public health challenge facing our generation. The number of people with dementia throughout the world today is estimated to be 44 million, and it is calculated to rise to almost double this by 2050 and more than triple the number by 2050.

When an elderly adult begins to suffer from dementia, functional impairment is progressive, and requires care to preserve minimal quality of life conditions, which in the majority of cases are provided by a family member. Over time the burden upheld by the caregiver may affect their everyday lives and is detrimental to their quality of life. Ersek et al.’s model (1997) accepts the concept the caregivers’ quality of life, as the result of a subjective assessment of positive or negative attributes characterising their own lives and which consist of 4 dimensions: physical, psychological, social and spiritual wellbeing.

When faced with a chronic degenerative disease, the family or some of its members feel seriously affected, suffer changes and adjustments to their daily activities and functions and if these are not favourable, become ill themselves (stress, depression, hypertension, gastritis, colitis, anaemia, lung conditions, etc.).

The family generally offer the main support, but it is usually one member who takes on the highest responsibility and this person may therefore end up being physically and emotionally overburdened with caring for the patient.

That person accepts the job of caring and attending to the needs of the person with dementia, overstraining themselves in their family and social roles, with repercussions on their physical, mental, financial, employment, family, social and free time areas. This may affect their health in a negative way and bring about a loss in their quality of life, as they adapt to new conditions for the improvement in the health and wellbeing of the person they are taking care of. In this regard, Zambrano and Ceballos identified the presence of overburden in the majority of dementia patient caregivers.

Given the above, we decided that the objective of our study was to determine the quality of life related to health and the degree of overburden in dementia patient caregivers.

Materials and methods

Quantitative, descriptive, correlational, transversal and intentional sample design study. The participants (n = 50) were the main caregivers of patients with moderate and severe dementia, recorded in the data base of the Neiva memory clinic.

Selection criteria: resident in the city of Neiva, caregiver for a period over 3 h, male or female over 18 years of age, a caregiver of a patient with dementia for a minimum period of one year. The participants were informed of the objectives and procedures to follow and were required to sign an informed consent form. Information was collected by nurses and psychologists, in the caregiver’s home.

Research was approved by the Ethics and Bioethics Committee of the Faculty of Health of the South Colombian University. The bioethical principles were taken into account: respect for human dignity, privacy, freedom of expression and feelings, confidentiality and reciprocity.

Instruments

Socio-demographic characterisation of caregivers (created by the Care Group to the chronic patient and their family of the Faculty of Nursing, National University of
The variables were as follows: gender; age of caregiver and receiver of care; educational level; marital status; occupation; socio-economic level; time as caregiver; hours dedicated to care; single caregiver; relationship between caregiver and patient; religion; support received; profession or work of the caregiver and other sources of support.

Caregiver’s quality of life\(^{1,15}\): a tool designed by doctor Betty Ferrel, with 37 items, 16 positive and 21 negative comprising 4 dimensions: physical (5 items), psychological (16 items), spiritual (7 items) and social (9 items).

The group of teaching staff of the UNAL Nursing Faculty, with authorisation from the author (2006), undertook the translation into Spanish, the adaptation to the Likert scale, semantic fine-tuning, validity of appearance and content. Reliability was established with 37 items and a base of 108 data in test and retest. Stability using the correlation coefficient calculation was 0.88, which indicated a strong positive correlation, and satisfied the stability criteria.\(^{16}\) The assessment of each item was made using a Likert scale from 1 to 4 (1: absence of any problems; 2: a few problems; 3: some problems; 4: a great deal of problems\(^{15}\)).

Caregiver’s overburden: abbreviated Zarit scale (1982). This measures the caregiver’s overburden. It assesses several factors such as: the impact of care, interpersonal relations and expectations of self-efficacy. This tool is used in several cities in Spain, adapted to primary care health areas with good effectiveness, with positive predictive levels of up to 100%. In Colombia studies on evaluation of the caregiver syndrome are known.\(^{1}\) It contains 22 Likert type questions with a range of response from 0 to 4 (never, almost never, sometimes, often, always). When the range of responses is under 46 this indicates no overburden, from 46 to 56 a slight overburden, over 56 an intense overburden.

Data analysis

Data were incorporated into a matrix created in Microsoft Excel 2016 (Id. of product 00339-23800-17648-AA064) and processes in the IBM SPSS statistical programme version 23 (Id. of product 00327-30436-78524-AA06M), with which descriptive statistics were generated (absolute and relative frequencies) for the qualitative variables, central tendency measurements and dispersion measurements for the quantitative variables. Prior to carrying out the hypothesis contrast it was confirmed whether the quantitative variables had a normal distribution with the Shapiro–Wilk test. For studying the correlation between numerical variables the Pearson or Spearman correlation was used, depending on the normality of the variable. In all cases a statistical significance level was taken into consideration when the \(p\) value was <.05.

Results

Table 1 presents the relevant socio-demographic characteristics of the main dementia patient caregivers \(n=50\). 80% were female, 52% with an age range between 36 and 59. The mean ± standard deviation (SD) of age was 73.6 ± 10.04 years; 34% had university qualifications; 54% were married; 78% had been a caregiver for over 7 months; 66% dedicated 24 h to caring; 30% were the spouses of the person they cared for and 20% had to make a change in their working lives to accommodate caring.

The perception of overburden for taking care of their family member is presented in Table 2, where 56% of participants never or almost never perceive of any overburden.

Table 3 shows the physical wellbeing with a mean ± SD of 10.18 ± 3.735, observing a positive perception in their state of health in their condition as main caregiver. Equally, in psychological wellbeing the score was 41.56 ± 6.774. The data recorded low relevance in this dimension, with a positive perception of it. In social wellbeing a mean of
19.62 ± 6.034 was observed, there is a positive perception of social relations, which has a positive effect on their quality of life as a caregiver; lastly, in the spiritual dimension there was a mean of 22.98 ± 3.217, a value which was congruent with a negative perception of spirituality, possibly leading to a loss of desire to do their work and at some time induce them to abandon the care of the person with dementia.

Bivariated analysis

The correlations in the quality of life dimensions (Table 4) confirm that the physical dimension is correlated proportionally to the psychological dimension (r = .537) and social dimension (r = .682); these correlations are highly significant. The contrary situation occurs between the physical and the spiritual dimension (r = .082), indicating low association (p = 0.572). The psychological dimension with the social dimensions correlation (r = .657) is highly significant (p = .000), indicating that there is association between these 2 dimensions whilst for the spiritual (r = .252) there is no correlation.

Discussion

The main socio-demographic characteristics of the caregivers are: the majority are female, with a mean age ± SD of 73.6 ± 10.04 years, a varied educational level and married. The predominant occupation is the home and independent employees or workers. 85% have cared for the patient since they were diagnosed with the disease. Those who are the receivers of care are family members. The support the caregiver has in order of ranking are: employee, spouse and nurse’s aide. The professions are varied, from housewives to professionals in different sectors. In the studies conducted by Romero Massa,7 de Valle et al.,18 Cerquera et al.,19 Mar et al.,20 Pascual Cuesta21 and Graziano et al.22 The socio-demographic characterisations reports similar results to those obtained in our study.

Both on the scale of overburden and quality of life normal distribution was found, through the Shapiro–Wilk test. Similar results were appreciated in the Espinoza y Jofre23 study in informal caregivers of dependent patients, with normal distribution and positive asymmetry.

Quality of life and overburden are significantly related. The contrary situation occurs with the socio-demographic variables, which are not directly associated. These 2 dimensions are mainly influenced by the physical and psychological health conditions of the patient and these factors have an impact on the caregiver, affecting their skills in exercising their function effectively, and putting the support system of their patient at risk.

Social, psychological and physical wellbeing in addition to quality of life are the protective factors for the caregiver. If the person exercising this role maintains their leisure activities, their financial situation, their loving and social relationships and support groups, the probability of presenting with overburden associated with their function as caregiver is reduced.

Despite the fact that 56% of caregivers have the perception that never and almost never are they overburdened

<table>
<thead>
<tr>
<th>Alternatives</th>
<th>Frequencies</th>
<th>Percentages</th>
</tr>
</thead>
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<tr>
<td>Never</td>
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<td>50.0</td>
</tr>
<tr>
<td>Almost never</td>
<td>3</td>
<td>6.0</td>
</tr>
<tr>
<td>Sometimes</td>
<td>11</td>
<td>22.0</td>
</tr>
<tr>
<td>Quite often</td>
<td>4</td>
<td>8.0</td>
</tr>
<tr>
<td>Almost always</td>
<td>7</td>
<td>14.0</td>
</tr>
<tr>
<td>Total</td>
<td>50</td>
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</tr>
</tbody>
</table>

### Table 3

General perception of quality of life and normality for each wellbeing, n = 50.

<table>
<thead>
<tr>
<th>Alternatives</th>
<th>No.</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Normality test</th>
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<tbody>
<tr>
<td>Physical wellbeing</td>
<td>50</td>
<td>5</td>
<td>20</td>
<td>10.18</td>
<td>3.735</td>
<td>.138</td>
</tr>
<tr>
<td>Psychological wellbeing</td>
<td>50</td>
<td>27</td>
<td>52</td>
<td>41.56</td>
<td>6.774</td>
<td>.4964</td>
</tr>
<tr>
<td>Social wellbeing</td>
<td>50</td>
<td>10</td>
<td>34</td>
<td>19.62</td>
<td>6.034</td>
<td>.06684</td>
</tr>
<tr>
<td>Spiritual wellbeing</td>
<td>50</td>
<td>15</td>
<td>28</td>
<td>22.98</td>
<td>3.217</td>
<td>.004274</td>
</tr>
</tbody>
</table>

### Table 4

Correlations and significance by dimension of the quality of life characteristic.

<table>
<thead>
<tr>
<th></th>
<th>Physical</th>
<th>Psychological</th>
<th>Social</th>
<th>Spiritual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>Pearson correlation</td>
<td>1</td>
<td>.537*</td>
<td>.000</td>
</tr>
<tr>
<td>Sig. (bilateral)</td>
<td></td>
<td></td>
<td></td>
<td>.572</td>
</tr>
<tr>
<td>Psychological</td>
<td>Pearson correlation</td>
<td>1</td>
<td>.682*</td>
<td>.000</td>
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<tr>
<td>Sig. (bilateral)</td>
<td></td>
<td></td>
<td></td>
<td>.078</td>
</tr>
<tr>
<td>Social</td>
<td>Pearson correlation</td>
<td>1</td>
<td>.657*</td>
<td>.000</td>
</tr>
<tr>
<td>Sig. (bilateral)</td>
<td></td>
<td></td>
<td></td>
<td>.232</td>
</tr>
<tr>
<td>Spiritual</td>
<td>Pearson correlation</td>
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<td></td>
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</tbody>
</table>

* The correlation is significant at level .01 (bilateral).
from looking after their family member, 44% of them perceive of overburden classified between sometimes, quite a lot and almost always. In Romero Massa the caregivers showed an absence of overburden at 48.8%; Grazziano et al. identified that 46% did not have an overburden or it was minimal and 38% presented with low to moderate, aspects which were in concordance with the findings from our research. According to these authors overburden is equally associated with cognitive impairment, the patient’s emotional symptoms and the guidance given to the caregiver. They acknowledge that those caregivers who receive guidelines for care perceive that they have a better quality of life in physical and psychological dimensions in addition to positive correlation with psychological and social dimensions.

De Valle-Alonso et al. reported that 58% experienced between slight and intense overburden and Cerquera et al. expressed that 34% experienced between slight and intense overburden. For these authors the presence of overburden is associated with factors such as: the state of illness in which the patient finds themselves, the non linking up to support networks and the lack of appropriate skills in exercising the caregiver role.

It is important to recognise that the burden of the caregiver must be considered as a matter of inequality in health due to the lack of health policies aimed at his or her protection. The role of the caregiver cannot therefore be solely defined in terms of procedures and tasks to be done. “Caring in the home of a family member is a stressful situation”.

Results prove that there is a tendency for 50% of the sample of caregivers to have a low perception of overburden. This is in keeping with the study conducted by Cerquera et al., which describes 65% with no overburden. According to them these people “have not let go of their personal lives or their interests, they are still hopeful about their future lives with expectations about what they can later achieve”.

These findings suggest a difficult overview for the person who takes on the role of the caregiver. Looking after a person with dementia has a negative impact on their health, and the situation becomes more complex as the cognitive impairment worsens and the demands for care increase. It is apparent that further studies relating to the caregivers of people with chronic diseases are required, as well as studies on the people cared for, so that their outcomes are reflected in health policies. These should aim to protect the caregiver and the person cared for in the interests of reducing overburden, improving quality of life and bringing about better conditions for the patient.

In a study by Vargas and Pinto 192 family member caregivers of people with Alzheimer were assessed. They found the psychological and social dimensions to be affected, whilst in the spiritual and physical dimensions there was a positive tendency. Our study results do not coincide with the findings reported by Vargas and Pinto, and this suggests that a more in-depth study needs to be made of these findings and the population analysed needs to be extended.

We may conclude that the higher the quality of life or social wellbeing, the lower the burden for the caregiver. Furthermore, no significant associations were found between the following factors: gender, caregiver’s age, patient’s age, educational level, marital status, occupation, time of diagnosis, time as caregiver and daily hours dedicated to caring. These variables may not directly affect the presence of overburden and its influence on the caregiver’s quality of life.

With regard to correlations, we found that in quality of life, the physical dimension is correlated with the psychological and social dimensions. Equally, there is a correlation between the psychological and social dimensions. In contrast, no correlation exists between the spiritual and the physical. These data may indicate better psychological and social wellbeing, a better perception of physical wellbeing, that leads to increased quality of life. It could be considered that stress, anxiety or anguish are somatised by people who accept the role of caregiver which leads to the presence of physical discomfort and an indication of a decline in their health.

Conclusions

Results lead us to conclude that a low percentage of caregivers experienced overburden which affected their quality of life. When quality of life is threatened the caregivers’ burden increases and a poor social wellbeing negatively affects this. It is therefore important that the main caregiver maintains their emotional and social relationships, in addition to their employment, leisure activities and contact with the outside world, to reduce the risk of feeling overburdened and changing their quality of life.

Nurses and health professionals must establish strategies which provide tools for building up favourable environments for caregivers. This will reduce overburden and improve their quality of life, as a balanced approach is sought between the caregiver and person cared for.

Study limitations

The sample size: only 50 participants met with the inclusion criteria. Results may not therefore be generalised.

Financing

This study was financed by the rector of research and social projection of the South Colombian University.

Conflict of interests

The research team has no conflict of interests to declare.

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